

# IS THERE A COST TO POOR COMMUNICATION IN CANCER CARE?: A CRITICAL REVIEW OF THE LITERATURE

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## SUMMARY

In this paper, the authors engage in a critical analysis of the existing empirical literature which addresses the impact of ineffective communication between cancer patients and clinicians. It is increasingly accepted that communication plays a significant role in many aspects of the care experience, and that poor communication can have a significantly negative influence on the patient's psychosocial experience, symptom management, treatment decisions, and quality of life. However, scant attention has been given to the idea that poor communication may also have an economic impact worthy of attention. This area has not been the focus of systematic inquiry or substantive critical consideration. On the basis of critical analysis of the limited empirical evidence that exists across a wide range of studies in related areas, the authors propose that the existential and material costs associated with poor communication in cancer care may well be considerable, and conclude with a call to mobilize a heightened enthusiasm for addressing the research challenges in this field. Copyright © 2005 John Wiley & Sons, Ltd.

**KEY WORDS:** communication; economic analysis; cancer; physician-patient communication; cancer care; oncology

## INTRODUCTION

There are significant data to indicate that effective communication is an asset to an effective cancer care system. However, there have been relatively few papers or reports on the impact that poor communication has on the care of the cancer patient and family (Ramirez, 2003). On the basis of our analysis of the literature, we identify a growing body of evidence that poor communication in cancer care seems unfortunately prevalent, and that it exerts a significant burden. In this paper, we undertake a critical integrative review of the existing evidence about the impact of poor communication and examine the general conclu-

sions that can be drawn about its effects upon patients, professionals and systems.

Although various relational and contextual methodological approaches have been effectively applied to studies of ethical issues in health care, they have been much less often applied to the study of such similarly complex matters as health care communication. Despite a general enthusiasm within the psychosocial research community for engaging in the study of communication in cancer care, the outcomes of cancer communication have not been well defined and its processes are difficult to interpret (Feldman-Stewart *et al.*, in press). While there has been some systematic study of the benefits of good communication, there is relatively little known about the absence of good communication or the presence of poor communication. In such research, data collection typically requires exhaustive techniques such as recording and analyzing clinical encounters, and analysis is complicated by the inherently multifaceted

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contexts within which cancer communication takes place. For these reasons, the cancer communication research community has not yet achieved uniformity or comprehensiveness in its methodological processes (Griffin *et al.*, 2003) and there are few established standards against which to appraise communication research approaches (Thorne, 1999).

In this paper we take an outcomes-oriented approach to define poor communication as those verbal and non-verbal aspects of the relationship between the clinician and patient which have the potential to create unfavorable outcomes. It is universally recognized that communication exists as a ubiquitous entity in cancer care delivery. It has the potential to be positive or negative in valence in that some communications will be helpful or effective in advancing cancer care objectives and others will not. Although there is little conceptual agreement about how to articulate the inherent distinctions, there is a common understanding that 'poor' communication can lead to a range of adverse outcomes for the patient (such as erosion of trust or misunderstanding of disease) or for the clinician (such as malpractice lawsuits) (Arora, 2003; Tattersall *et al.*, 2002; Vardy and Tannock, 2004). Thus, in searching the literature for an association between poor communication and outcomes, we extrapolate from range of evidence forms as well as that which is explicitly assumptive or value laden. Although no body of hard evidence exists from which to extract an economic analysis, we propose a consideration of economic cost as an additional adverse outcome of poor communication in cancer care.

#### UNTOWARD OUTCOMES ASSOCIATED WITH POOR COMMUNICATIONS

Clearly recognized within the empirical literature is a set of assumptions that poor communication in cancer care is not merely a matter of bad manners or the absence of social graces, but rather something fundamental to the effectiveness of the clinical encounter. In general, the empirical literature reveals the assumption that poor communication may have a number of untoward effects upon the patient and the treatment process, including effects upon the nature and quality of information transmission, the enactment and outcome of decisional processes, and the psychosocial

experience with which the patient is confronted. Here we provide an overview of the kinds of claims that are made within this body of literature to provide a context for our subsequent consideration of the matter of costs.

#### *The informational context*

Among the most commonly studied aspects of communication is its influential role in providing patients with information relative to their disease and the choices to be made in its management (Jenkins *et al.*, 2001). It has long been established that patients are often dissatisfied with the amount and nature of information they receive (Bilodeau and Degner, 1996; Chan and Woodruff, 1997; Fallowfield *et al.*, 1995; Hinds *et al.*, 1995; Luker *et al.*, 1996; Manfredi *et al.*, 1993; Meredith *et al.*, 1996; Paraskevaidis *et al.*, 1993; Suominen *et al.*, 1994; van der Kam *et al.*, 1998; Veronesi *et al.*, 1999). Although it is well recognized that, while information needs are highly individualized, this individualization of information is rarely achieved (Degner *et al.*, 1997; Feldman-Stewart *et al.*, 2000). A particular context in which the critical role of communication in information transmission has attracted considerable attention is diagnostic and prognostic information (Dunn *et al.*, 1993; Horikawa *et al.*, 1999; Lobb *et al.*, 1999), more specifically 'breaking bad news' (Faulkner *et al.*, 1995; Holland and Almanza, 1999; Kim and Alvi, 1999; Parker *et al.*, 2001; Ptacek and Eberhardt, 1996). It has commonly been reported that, from a patient perspective, clinician skills with these particular communication encounters tend to be lacking (Caruso *et al.*, 2000; Chaitchik *et al.*, 1992; Merriman *et al.*, 1997; Sardell and Trierweiler, 1993). Among the effects of such communication deficits are significant misunderstandings among patients about the nature and seriousness of their disease (MacKillop and Quirt, 1997).

Much of what is understood about breaking bad news is based upon clinical wisdom rather than empirical evidence (Burton and Parker, 1997; Dowsett *et al.*, 2000; Girgis and Sanson-Fisher, 1995, 1998; Holland and Almanza, 1999), and the relationship between patient preferences and existing communication guidelines or principles is not well understood (Baile *et al.*, 2000; Burton and Parker, 1997; Butow *et al.*, 1996; Dowsett *et al.*, 2000; Ellis and Tattersall, 1999; Ford *et al.*, 1996; Gattellari *et al.*, 1999; Girgis and Sanson-Fisher,

1995, 1998; Loge *et al.*, 1997; Salander, 2002; Schofield *et al.*, 2003).

### *The clinical context*

A related context in which poor communication has been found to have a particularly detrimental impact is on the quality of decisions patients are able to make in relation to their course of treatment (Elit *et al.*, 1996; Gafni *et al.*, 1998; Liang *et al.*, 2002; Roberts *et al.*, 1994; Silliman *et al.*, 1997). Poor communication is known to increase the use of alternative and/or unnecessary treatment (Tasaki *et al.*, 2002), and it has also been linked with inadequate pain relief (Berry *et al.*, 2003). Among the most commonly documented associations in this field is a relationship between poor communication and reduced patient satisfaction (Ong *et al.*, 2000; Zachariae *et al.*, 2003). Further, the fear and anxiety incurred in patients who have experienced poor communication is believed to lead to further demands upon the system in terms of the time and effort required to counteract the resultant emotional distress and misinformation it causes (Humphreys, 2000).

Although the information literature primarily reflects that which is transmitted from the professional to the patient, there is also some recognition within the literature that, because communication is interactive, the behavior of the patient may have an impact upon the clinician. For example, it has been noted that patient coping styles (monitoring or blunting) seem to change the way in which physicians communicate during the oncologic consultation (Ong *et al.*, 1999), that patients' responses to verbal cues may influence the language used in information transmission (Friedrichsen *et al.*, 2002), and that patient assertiveness may significantly affect clinician decisions related to diagnostic testing (Krupat *et al.*, 1999).

It has also been well documented that communication difficulties impede the recruitment of patients to clinical trials (Brown *et al.*, 2004; Fallowfield and Jenkins, 1999). Since clinical trials represent the gold standard of treatment, and inadequate recruitment processes delay the introduction of efficacious new approaches, this may represent an important mechanism by which communication may be linked to sub-optimal clinical outcomes.

### *The psychosocial context*

Another significant body of literature associates poor communication with a number of untoward psychosocial sequelae for cancer patients. These include heightened anxiety and depression (Ellis and Tattersall, 1999; Fogarty *et al.*, 1999; Paraskevaidis *et al.*, 1993), poor psychological adjustment (Bishara *et al.*, 1997; Mager and Andrykowski, 2002; Roberts *et al.*, 1994), ineffective coping (Finset *et al.*, 1997), hopelessness (Sardell and Trierweiler, 1993), and reduced quality of life (Kreitler *et al.*, 1995; Ong *et al.*, 2000).

It is also commonly recognized that poor communication skill reduces the clinician's capacity to recognize psychiatric morbidity in cancer patients (Detmar *et al.*, 2002; Fallowfield *et al.*, 2001; Ford *et al.*, 1994; McCool and Morris, 1999; Newell *et al.*, 1998; Ronson, 2004; Sollner *et al.*, 2001), in part due to the reduced likelihood that patients will disclose their concerns (Maguire *et al.*, 1996; Rogers and Todd, 2002). In addition, it is believed that poor communication is associated with heightened anger toward health care professionals, and therefore litigiousness (Hotson, 2003; Schafer *et al.*, 2002; Stead *et al.*, 2003).

## THE COST OF POOR COMMUNICATIONS

As clinicians, researchers, administrators and educators, having surveyed the literature documenting the nature and scope of negative impacts purported to derive from poor communication, we find it reasonable to extrapolate that poor communication may well exert a significant burden upon the patient, the clinician, and also upon the service delivery system. In order to further the dialogue with regard to how we might begin to estimate the costs associated with such a burden, we now turn in more detail to an examination of three main categories within which significant costs may occur. These include costs to the patient associated with unnecessary psychosocial distress for the patient, costs to the system associated with unnecessary treatment, and costs to the clinicians and the care system as a whole associated with the indirect effects of poor communication. In relation to each, we examine the available literature to extract any preliminary evidence that might help

us better understand the possible magnitude of such costs.

### *The cost of unnecessary psychosocial distress*

Three large cancer screening studies have demonstrated the prevalence of psychosocial distress to be consistently in the range of 35–45% of all cancer patients (Carlson *et al.*, 2004; Cella, 1998; Zabora *et al.*, 2001). In 1998, Ashbury and colleagues (Ashbury *et al.*, 1998) noted that unresolved emotional issues were associated with five times the frequency of using community health services, twice the rate of visits to an emergency department, and also more prevalent use of complementary medicine, as well as third and fourth line chemotherapy. Despite the prevalence of significant psychosocial distress rates and the potential costs associated with failure to attend to it, rates of referral for psychosocial care are consistently low. Vachon suggested two possible reasons: (1) the inability of physicians to identify psychosocial problems and (2) the belief among some clinicians that explicit psychosocial intervention is not sufficiently helpful to be justifiable as a core element of cancer care (Vachon, 1998).

As we have indicated, economic analyses of aspects of communication and or psychosocial distress in the cancer patient are in the very early stages and are conceptually problematic and fragmented. Where they have been attempted to date, they have produced confusing conclusions. For example, it has been demonstrated that, although patients prefer it, the cost of mailing out an extensive information package prior to initial consultation cannot be justified by a measurable benefit in psychological distress levels (Mohide *et al.*, 1996). Similarly, an RCT of routine telephone follow-up after radiotherapy found minimal difference in perceived support among those receiving an experimental enhanced follow-up regime as compared to those who did not (Munro *et al.*, 1994). Within the clinical oncology encounter itself, we see evidence of considerable concern for the cost implications of any recommendations that rely upon communication strategies. For example, Gafni *et al.* (1998) demonstrated that there are two primary models of enhancing decision-making — transferring information about choices to be made from the physician to the patient or transferring

information about patient preferences from the patient to the physician. While both are effective in ensuring effective decision-making processes, they report that the latter is the more time-consuming and therefore least cost effective (Gafni *et al.*, 1998). Thus, the few studies that have examined aspects of the clinical cancer care consultation with an economic analysis in mind have not produced a convincing portrait of the value of expanded communication for preventing unnecessary psychosocial distress.

In contrast, there is an emerging literature examining the cost offset of explicit attention to the psychosocial dimension of cancer care (Carlson and Bultz, 2002, 2003). In a large meta-analysis of 91 medical-cost-offset studies related to psychological intervention for patients with various illnesses, the authors concluded that 90% found a significant reduction in utilization of medical services, which could represent an enormous global cost savings (Chiles *et al.*, 1999). In the cancer context, one recent Canadian study has effectively demonstrated a health plan billings reduction of over 20% at two-year follow-up for those breast cancer patients who were offered a cognitive-behavioral psychosocial group as compared with those who were not (Simpson *et al.*, 2001). This study was believed to be the first to demonstrate that focused consideration of the psychosocial dimension of the illness experience can reduce overall health care costs in a cancer population. Although cost estimates are not a typical outcome measure in studies of psychosocial outcomes in cancer, other studies have similarly reported reductions in health care contacts following psychosocial interventions and supportive measures (Rosenberg *et al.*, 2002). These cost savings are understood to be realized from fewer unnecessary office visits, medical procedures, diagnostic tests, and hospital admissions when appropriate psychotherapeutic interventions are readily available (Spiegel, 1994). Interestingly, despite the evidence of a high prevalence of psychosocial distress, emotional care for the cancer patient remains poorly supported by third party payers in the United States, and by provincial cancer programs in Canada. There seems clear indication that efforts by cancer care clinicians to minimize unnecessary psychosocial distress and to support patients where distress is problematic are not only compassionate, but also quite likely cost effective (Carlson and Bultz, 2002, 2003).

### *The cost of unnecessary treatment*

Although it is difficult to create consensus around specifically which treatments are or are not necessary, it is also commonly recognized that poor communication can be associated with conditions under which late-stage treatment is more aggressive and the frequency of futile procedures is increased (de Haes and Koedoot, 2003). Because of this, patient–physician communication problems have become a well recognized barrier to quality end-of-life cancer care (Daugherty, 2004; Larson and Tobin, 2000; Yabroff *et al.*, 2004). For example, a recent ethnographic study of 35 patients with small cell lung cancer found that physician preference for the most active course of treatment contributed to a ‘recovery plot’ in which the patient and clinician colluded to avoid difficult disease information and engage in false optimism about recovery (The *et al.*, 2001). Estimates of the frequency with which problematic communications occur in the late-stage cancer context suggest that this may be an unfortunately common occurrence. In a survey of health care professionals caring for 1326 patients at the end of life in three countries, one research team documented reports of severe communication problems as part of team assessments in the care of 40% of these patients (Higginson and Costantini, 2002). Despite the significant costs arising from unnecessary resuscitation, intensive care and active treatment, and the detrimental that such procedures can have on quality care, the communication skills required for end-of-life decision-making are still not taught in a majority of medical schools (von Gunten *et al.*, 2000).

An emerging body of evidence is pointing to a relationship between communication problems and the costs inherent in increased use of third and fourth line chemotherapies in advanced cancer. On the basis of a recent study of patients with lung cancer, the authors suggested that, although these clinical practice patterns accounted for no improvement in survival rates, they had the potential to produce a 100% overall care cost differential (Hoverman and Robertson, 2004). Emanuel and colleagues demonstrated that almost 25% of a population of medicare patients received chemotherapy in the last six months of life (Emanuel *et al.*, 2003). Although the costs of what are generally considered non-essential therapies must be considered in the context of the psychosocial benefits that may arise from the sense that

something is being offered (McLaghlan *et al.*, 1999), it seems probable that unnecessarily aggressive or futile treatment is more prevalent where effective communication between the patient and physician is not achieved. Many oncologists struggle with how to talk to patients about prognosis and how to transition patients to palliative care (Back *et al.*, 2003; Baile *et al.*, 2002), and this dynamic may exclude patient decision-making regarding chemotherapy in advanced disease. Some patients press for aggressive treatment creating ethical dilemmas for clinicians or resulting in their trying additional treatments which have low cost-benefit ratio (Yabroff *et al.*, 2004). Paradoxically, some physicians offer aggressive treatment as a means by which to avoid facing their inability to cure (de Haes and Koedoot, 2003). The available evidence is scant, and in the case of some cancers, active palliation in late-stage disease does seem consistent with improved emotional function and global quality of life (Doyle *et al.*, 2001). However, it is also believed that many of the burdens associated with late-stage cancer can be ameliorated by physicians willing to listen to and empathize with patients’ concerns (Emanuel *et al.*, 2000).

Another cost associated with communication breakdown is the direct and potential indirect cost of complementary and alternative medicine (CAM). CAM use is high among cancer patients, especially among those who are highly distressed, and a majority of patients using CAM do not discuss it with their oncologists (DiGianni *et al.*, 2002; Honda and Jacobson, 2005). Not only does ineffective doctor-patient communication increase the extent to which patients may revert to costly alternatives, but also heightens patients’ exposure to possible drug interactions and other untoward effects of such choices (Chrystal *et al.*, 2003). While the majority of CAM use is complementary, in the sense that it is associated with concurrent involvement in conventional care, unsatisfying or alienating relationships with health care providers increases the prevalence of declining all or part of recommended cancer treatment (Shumay *et al.*, 2001).

### *The cost of indirect system distress*

Beyond the costs that may arise as a result of untoward psychosocial distress and unnecessary treatment, it is possible to extrapolate further to

the possibility of costs to the health care system as a result of poor or inadequate professional–patient communications. It has been well recognized that the work of clinical cancer care is exceptionally emotionally demanding, requiring continuous interaction with patients for whom curative treatment may be ineffective in a high proportion of cases (Graham and Ramirez, 2002). While it is well documented that poor communication in the clinical context creates considerable emotional distress for patients and their families, it has also been noted that health care providers may suffer similar effects when communication breakdown occurs (Davis *et al.*, 2003). For example, poor quality physician–patient communication is implicated in higher stress and burnout levels among cancer clinicians (Armstrong and Holland, 2004; Gordon, 2003; Ramirez *et al.*, 1995; Razavi and Delvaux, 1997). Studies of senior clinicians working in cancer care reveal that they perceive their burnout to be a direct result of feeling inadequately trained in communication skills (Fallowfield and Jenkins, 1999; Maguire and Pitceathly, 2003; Razavi and Delvaux, 1997).

Various recent studies have documented a range of factors leading to increases in communication breakdown within the clinical cancer context, including managed care, which shifts the role of health care team members and fragments care (Bourjolly *et al.*, 2004) and leads to inadequate utilization of resources such as advance care directives and ethical consultation (Griffin *et al.*, 2003). Effective cooperation between the various members of the health care team is also known to be compromised by poor communication. Such effects as confusion within the team and a loss of confidence among team members derive from communication breakdown (Fallowfield and Jenkins, 1999).

Thus, although quantification of indirect system effects arising from poor communication is a daunting challenge, the preliminary evidence suggests that poor communication may well be strongly implicated in a wide range of problems associated with the competence, satisfaction and effectiveness of individual clinicians, with the smooth and efficient operations of the cancer care processes, and with the optimal cooperation and collaboration between various members of the cancer care team. Each of these has a powerful potential impact upon quality of patient care, and may well be associated with significant additional tangible and intangible costs.

## CONCLUSIONS

Although it is well recognized that cancer represents a crisis in the lives of those affected, our pressing concern lies with those aspects of the crisis that can be prevented or ameliorated. As a result of critical analysis of the available empirical literature, we assert that the negative consequences of poor communication are substantial and broad in scope. Further, we can extrapolate that poor communication exerts costs that are potentially enormous, and may include economic, social, psychological, emotional, and collateral costs to the patient, the patient's support network, the clinicians, the cancer care system, and to the larger society itself.

Our analysis extends the accepted view that attention to good communication will be consistent with best practice to examine the corollary argument, which is that interrupting and transforming poor communication may constitute an imperative that is not only moral but also economic within our cancer care delivery systems. From a pragmatic perspective, we appreciate that mobilizing the cancer research agenda beyond genetic mutation and dysfunctional cell biology is unlikely to occur in the absence of a convincing argument that the 'soft and fuzzy' variables such as communication actually matter. Although the limitations inherent in the available empirical evidence make explicit claims about the direct costs of poor communication problematic, we believe that this review of the existing evidence makes a strong case for the assumption that poor communication has a detrimental effect upon patients and to the cancer care system, and that these effects will exert both human and economic costs.

Although we argue for the advancement of an economic analysis of the implications of poor communication in cancer care, we also fully recognize the inherent methodological challenges associated with the study of complex philosophical and ethical phenomena such as the human encounters within cancer care. Further, we appreciate that the nature of evidence in this field of inquiry makes it frustratingly resistant to evaluation using the traditional approaches that are available in relation to other aspects of cancer medicine. Despite these challenges, we hope that our preliminary analysis contributes something to the larger dialogue with regard to priorities in psychosocial support for cancer patients and

improving the quality of cancer care delivery. We see communication in cancer care at the heart of that agenda. On the basis of our critical review of the empirical evidence available, we conclude that ignoring poor communication as a priority issue in cancer care delivery would be both misguided and costly.

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